

# **Director's Council of Public Representatives Report to the ACD**

December 4, 2009

Elizabeth Furlong, J.D., Ph.D., R.N.

John C. Nelson, M.D., M.P.H.

# *Engaging the Public in Research Week*

## *October 26–30, 2009*



- Partners in Research (PIR) Investigator Workshop, October 26–27.
- NIH Staff Training in Extramural Programs (STEP) Forum: Nuts-and-Bolts of Community Engagement in Research, October 28.
- Meeting of the NIH Director's Council of Public Representatives, October 30.

# Staff Training in Extramural Programs October 28, 2009

## Panelists:

- **Dr. Syed M. Ahmed**, *COPR*
- **Ms. Ann-Gel Palermo**, *COPR*
- **Dr. Sarah J. Gehlert**, *Brown School of Social Work, Washington University in St. Louis*
- **Dr. Francesco S. Celi**, *National Institute of Diabetes and Digestive and Kidney Diseases*
- **Dr. Lisa Rey Thomas**, *Alcohol and Drug Abuse Institute, University of Washington*
- **Dr. Claudia R. Baquet**, *School of Medicine, University of Maryland, Baltimore*



**Building 10, Masur Auditorium,  
NIH Campus, Bethesda, Maryland**

**October 28, 2009**

*Nuts-n-Bolts of Community Engagement in Research*

**NIH Director's Council of Public Representatives  
Celebrating a Decade of Service, 1999-2009**

# COPR Work Group Day Information Gathering Session

## Speakers:

- **Ms. Philippa Yeeles**, *United Kingdom Clinical Research Collaboration*
- **Dr. Adel Mahmoud**, *Princeton University*
- **Dr. Rona Hirschberg**, *National Institute of Allergy and Infectious Diseases*
- **Dr. Amy P. Patterson**, *NIH Office of Science Policy*
- **Dr. Robert Croyle**, *National Cancer Institute*
- **Dr. Donna Jo McCloskey**, *National Center for Research Resources*
- **Mr. John Burklow**, *Office of Communications and Public Liaison, NIH*

# COPR Work Group Day

## Community Engagement in Research Implementation (CERI) Work Group

- NIH formed CERI in response to COPR recommendations on the role of the public in research.
- Charge: to review recommendations and identify NIH programs and processes that may be appropriate for application/incorporation.
- 17 members representing a cross-section of NIH staff covering seven key areas.

# October 30, 2009, Meeting

- Current Directions in Research on Complementary Medicine
  - **Dr. Josephine Briggs**, *Director, National Center for Complementary and Alternative Medicine*
- International Biomedical Research Initiatives
  - **Dr. Roger I. Glass**, *Director, John E. Fogarty International Center*
- Comparative Effectiveness Research Initiatives
  - **Dr. Richard J. Hodes**, *Director, National Institute on Aging*

# COPR Celebrates a Decade of Service

## [www.copr.nih.gov/anniversary](http://www.copr.nih.gov/anniversary)

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## Director's Council of Public Representatives

Celebrating a Decade of Service, 1999-2009

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### COPR's 10-Year Anniversary

#### COPR TIMELINE

**November 1997**  
**Congress Directs Action to the HHS Secretary**  
Congress directed the Secretary, U.S. Department of Health and Human Services, to commission the Institute of Medicine to "conduct a comprehensive study of the policies and processes used by the NIH to determine funding allocations for biomedical research." The study would examine:

1. the factors or criteria used by the National Institutes of Health to determine funding allocations for disease research
2. the process by which research funding decisions are made
3. the mechanisms for public input into the priority setting process
4. the impact of statutory directives on research funding decisions

- In Conference Report accompanying HR 2204, FY98, Labor, Health and Human Services, and Education, and Related Agencies

1998 | 1999 | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009

[COPR Timeline :: Accessible Format](#)

#### Reflections

NIH Director's Council of Public Representatives  
Celebrating a Decade of Service, 1999-2009

[Reflections: Celebrating a Decade of Service :: Accessible Format](#)

#### Engaging the Public in Research Week

[Engaging the Public in Research Week](#)

*Timeline and Reflections presentations require [Flash Player 10](#) or later. Accessible formats require [Acrobat Reader](#).*

# Role of the Communications Work Group

- Promote awareness about NIH to the public.
- Act as a vehicle for communication from the public to NIH.
- Recommend communication strategies that support the work of the COPR.

Action: Help NIH seek broad public input.

# Request for Information on Consumer Health Information- Seeking Behaviors

- **Goal:** to obtain insight and better understanding of the health information needs and information-seeking behaviors of NIH health consumer audiences.
- **Outcome:** The information gathered will assist the NIH in developing and disseminating health, medical and scientific information to a broader variety of audiences.

<http://nihhealthinfoRFI.nih.gov>

## **Request for Information on Consumer Health Information- Seeking Behaviors (cont.)**

**Seeks broad public input via Request for Information (RFI). Benefits of this process:**

- Responds to the presidential directive for transparency and open government.
- Potential to reach a wide and diverse group of health consumers, providers, and organizations, especially by involving COPR members' constituencies.
- Identifies a process for future information-gathering initiatives.
- Uses the "ambassador" role of the COPR.

# Closing December 30, 2009

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## Consumer Health Information

[en Español \(Solo para imprimir\)](#)

### Quick Links

- [Request for Information](#)
- [Print-Only PDF \(English\)](#)
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### Request for Information (RFI)

#### We would like to hear from you!

The NIH Office of Communication and Public Liaison (OCPL) and the NIH Director's Council of Public Representatives (COPR) have partnered to develop a Consumer Health Information RFI in response to a Directive by President Barack Obama to all Federal agencies calling for greater transparency, public participation, and collaboration.

In conjunction with the NIH goals for public input and effective dissemination of science-based health resources and information to the public, the RFI will provide insight and better understanding of the health information needs and information-seeking behaviors of NIH health consumer audiences. Information gathered will assist the agency in developing and disseminating health, medical, and scientific information to a broader variety of audiences.

To begin and submit your responses, click the link below and read the **Privacy Act Statement**.

[Privacy Act Statement](#)

 National Institutes of Health (NIH)  
9000 Rockville Pike  
Bethesda, Maryland 20892

 Department of Health and Human Services

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# Distribution Channels Used to Date

- COPR and Alumni members.
- NIH YouTube and Twitter.
- NIH constituency databases (individual consumers, health organizations, universities and colleges, hospitals and research centers, patient advocacy organizations, and professional societies).
- NIH Public Bulletin.
- NIH public liaison officers and communication directors.
- Publications of the NIH Institutes and Centers (e.g., National Library of Medicine magazine, Clinical Center News, NIH Record, constituency newsletters).
- Meetings attended by NIH staff.

# COPR Member Activities (April 2009–October 2009)

CBS Cares



CBS Cares/ HAIR Osteoporosis Campaign



CBS Cares - HAIR / Osteo



# COPR Member Activities (April 2009–October 2009)

COPR Alumnus Douglas Yee, M.B.A., (pictured at right) arranged for National Human Genome Research Institute Acting Director Alan Guttmacher, M.D., to speak to two high school anatomy classes at Punahou School in Hawaii. Mr. Yee's involvement demonstrates the continued support COPR alumni provide to both NIH and their communities.



# COPR Member Activities (April 2009–October 2009)

COPR Alumna Valda Ford spread The Heart Truth messages locally and internationally.



## COPR Going Forward

- Exploration of new topics important to the NIH Director and the public:
  - Obesity.
  - Human subjects projections.
  - Communication of research stories.